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Empowering Ontario's long-term care residents to shape the place they call home: a codesign protocol

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ABSTRACT

Background Canada's long-term care (LTC) homes were founded on an institutional model that viewed residents as passive recipients of care. Many homes continue to follow this model leaving residents removed from operational decision-making within their homes. However, involving residents in the design of their LTC home's environment, programmes and operations can improve the residents' quality of life and other outcomes. This codesign project creates a toolkit/resource for LTC homes to facilitate meaningful resident engagement in their home's organisational design and governance.

Method This three-part project consists of a scoping review, qualitative interviews, toolkit/resource development and prototyping. In part 1, we conduct a scoping review to synthesise existing knowledge on approaches to engaging LTC home residents in organisational design and governance of their LTC homes, as well as explore barriers, challenges and facilitators of engagement, considerations for diversity and cognitive change, and approaches to evaluation. In part 2, we will have interviews and focus groups with residents, team members (staff) and administrators to assess community capacity to implement and sustain a programme to engage LTC residents in organisational design and governance of their LTC homes. The third part of our project uses these findings to help codesign toolkit(s)/resource(s) to enable the engagement of LTC residents in the organisational design and governance of their LTC homes.

Ethics and dissemination The project is conducted in partnership with the Ontario Association of Residents' Councils. We will leverage their communication to disseminate findings and support the use of the codesigned toolkit(s)/resource(S) with knowledge users. We will also publish the study results in an academic journal and present at conferences, webinars and workshops. These results can influence practices within LTC homes by inspiring an organisational culture where residents help shape the place they call home. The interviews and focus groups, conducted in part 2, have been submitted to the University Health Network Research Ethics Board.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The community-based cocreation of the project ensures that the focus is relevant and applicable to long-term care homes.
⇒ Collaboration with the community partner, The Ontario Association of Residents' Councils, furthers the knowledge dissemination reach to end-users.
⇒ The breadth of the scoping review will address a research gap in long-term care home resident involvement in organisational design and governance.
⇒ The grey literature search may be biased towards North American publications.
⇒ Toolkit(s)/resource(s) development is tailored towards applicability within Ontario's long-term care system and may not be equally applicable in other contexts.

INTRODUCTION

Long-term care (LTC) homes, commonly known as nursing homes or care homes, are places where people receive 24-hour care and support with activities of daily living.[1] Nearly 200 000 Canadians live in over 2000 LTC homes across the country.[2 3] In the province of Ontario, approximately 80 000 people reside in 626 LTC homes.[4] Most LTC residents are older adults with complex health needs, including sensory, mobility and cognitive impairments.[4 5]

LTC homes were built and modelled on an acute care system, not a 'home' or social model.[6] Residents are not typically regarded as contributors; rather, they are seen as vulnerable, passive recipients of care. Despite efforts to formalise and protect the residents' roles in their LTC homes, the negative effects of ageism and ableism persist. Engaging LTC residents will inform education, policy, service delivery and governance within LTC homes and the broader healthcare system. Yet, little is known about effective approaches to engagement of this population. Reviews of research have examined quality improvement in LTC homes[7 8] or ways LTC residents can engage in research[9] and health practice guideline development.[10] To our knowledge,

Table 1 Adaptation of Carman *et al*'s[11] patient engagement framework to LTC homes and residents

Level of engagement	Continuum of engagement		
	Consultation →	Involvement →	Partnership
Direct care (resident level)	Residents receive information about their health and daily routines	Residents are asked about their preferences for care and daily routines	Decisions are based on resident preferences and, if applicable, family input, medical evidence and clinical judgement
Organisational design and governance (home level)	LTC homes survey residents about their experience in the home	LTC homes involve residents as advisors, committee members or other similar capacities	Residents colead LTC home committees
Policy making (system level)	Public agency conducts focus groups with residents to ask opinions	Residents' recommendations about research priorities are used by a public agency to make funding decisions	Residents have equal representation on agency committees that make decisions about how to allocate resources within the LTC sector
	Factors influencing resident engagement: ► Residents (eg, beliefs about roles, literacy, education, capacity) ► LTC home (eg, policies and practices, culture, leadership) ► Sector (eg, national, provincial and local regulations and policy) ► Societal attitudes (eg, ageism, ableism)		

Engagement can range in scope and level of involvement from consultation to partnership. For our project, we focus exclusively on resident involvement and partnership in organisational design and governance.
LTC, long-term care.

previous reviews have not addressed the role of residents in the organisational design and governance of their LTC homes. This includes strategies and contextual factors that enable engagement, and outcomes or experiences for LTC residents and homes.

We are interested in exploring resident engagement at the home level and as described in Carman *et al*'s patient engagement framework (table 1), such as where LTC residents might contribute as advisors, committee members or other similar capacities (ie, involvement) or residents colead LTC home committees (ie, partnership).[11] Three key factors motivate our focus on resident engagement in organisational design and governance. First, residents identify engagement as a priority. Previous research reports that LTC residents seek opportunities for meaningful activity, including making contributions to their LTC homes[12] and communities. These opportunities for engagement and autonomy encompass a critical domain in their quality of life.[13] Second, the proposed project is timely in light of new legislative requirements for LTC homes in Ontario (Fixing Long-Term Care Act, 2021). This legislation requires LTC licensees to formalise a process to engage residents in quality improvement and operational planning. Third, the focus on engagement aligns with the culture change movement, which emphasises resident-centred and resident-directed values and practices. The voices of older adults and the people who work with them need to be valued and respected.[14 15]

The current project aims to inspire transformation in LTC homes' culture by exploring, consolidating and promoting ways for residents to be engaged in their LTC homes' organisational design and governance. Within the knowledge-to-action framework,[16] the current project represents collaborative 'knowledge creation' that is supported by an 'action cycle', or application, led by our community partner, the Ontario Association of Residents' Councils (OARC). The specific objectives are to:

1. Synthesise existing knowledge on approaches to engaging LTC home residents in organisational design and governance of their LTC homes.
2. Assess community capacity to implement and sustain a programme to engage LTC residents in organisational design and governance of their LTC homes.
3. Codesign toolkit(s)/resource(s) to enable the engagement of LTC residents in the organisational design and governance of their LTC homes.

METHODS AND ANALYSIS

Our community-based participatory research[17] project integrates cocreation[18 19] and aligns with concepts of patient-oriented research[20] and integrated knowledge translation.[19] Stakeholders will guide the research project, including dissemination methods. We have integrated codesign, a methodology to engage end-users to assist in developing products or services through knowledge sharing.[21–23] By incorporating stakeholder feedback, this methodology enhances the impact, usefulness and benefit of the research.[24 25] Cocreation allows the project team to integrate the end-users' perspectives and experiences and develop shared values.[26]

This three-part codesign project consists of a scoping review, qualitative interviews and focus groups, and toolkit/resource development. These components

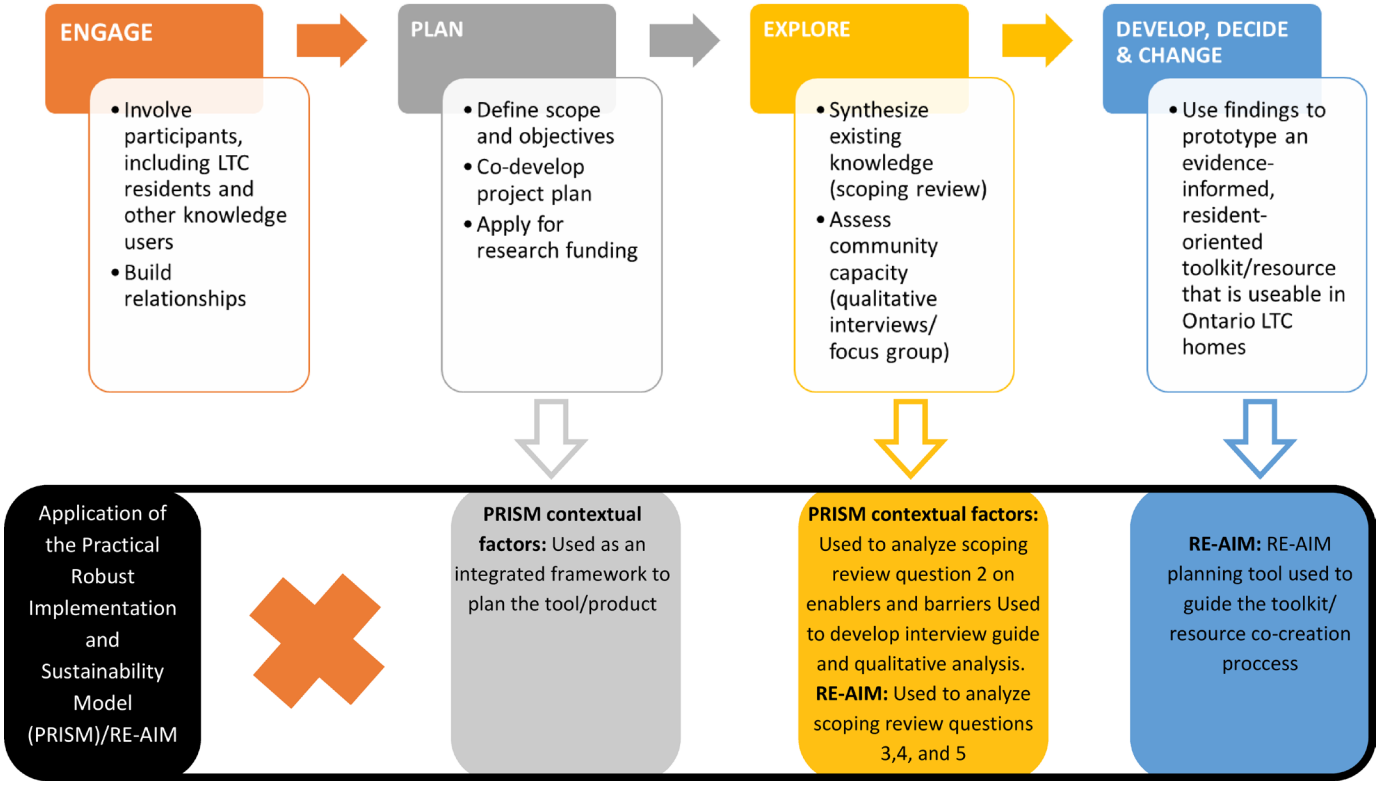

Figure 1 Overview of project components in alignment with the codesign steps and application of the PRISM/RE-AIM model. Step 1: ENGAGE. In this step, the research team builds relationships with OARC and their resident volunteers. Step 2: PLAN. In this step, we define the research scope, objectives and methods. The PRISM contextual factors are used as an integrated framework to guide how to plan for the creation of a toolkit/ resource. Step 3: EXPLORE: We explore existing resident engagement practices that are documented in the literature through a scoping review, as well as current practice and community readiness through interviews/ focus groups. We apply components of the PRISM/REAIM framework to analyse the scoping review questions. Steps 4–6: DEVELOP, DECIDE and CHANGE. At this step, we will iteratively cocreate and prototype a toolkit/ resource. We will apply the RE-AIM planning tool to guide the cocreation process. PRISM, Practical Robust Implementation and Sustainability Model; RE-AIM, Reach, Effectiveness, Adoption, Implementation, Maintenance.

are situated within the codesign steps of engage, plan, explore, develop, decide and change (figure 1).[22] We have engaged with our key stakeholder groups: LTC residents, staff (hereafter referred to as 'team members') and administrators by establishing relationships through OARC. Authentic relationships underpin the work because these partnerships will help guide all subsequent steps in the codesign process. Collectively, with stakeholders, we have planned the current project's objectives by obtaining peer-reviewed research funding and preparing the project protocol. We will explore the end-user experience through the scoping review (part 1) and interviews and focus groups (part 2).[22] For the latter three steps, develop, decide and change, we will codevelop toolkit(s)/resource(s) to facilitate the engagement of residents in LTC homes.

Patient/public involvement

This project is being conducted in partnership with the OARC, a non-profit organisation funded by the Ontario government to provide support, education and resources to residents, Residents' Councils and LTC home workers. This community organisation, which has a direct connection with residents living in LTC homes across Ontario, is engaged through all steps of the project, including priority-setting, conduct and knowledge dissemination.[27] OARC was involved in determining the key concept of research and continues to inform and engage others, including LTC residents, team members and administrators, in defining the direction of the research. The project team includes researchers, trainees, OARC's team members and residents of LTC homes; all members will be offered opportunities to become involved in different aspects of the project, but with the flexibility to accommodate individual strengths, needs and preferences.

We will involve four OARC groups (see table 2) during the conduct of the project: the Education Committee, the Resident Expert Advisors and Leaders group, Resident Forums and the Residents' Council Assistants Forum. These groups will assist with refining the research questions, interpreting the findings and contextualising the findings for different audiences. The groups will also inform the development and dissemination methods of the corresponding toolkit(s)/resource(s). Approaches to involvement were informed by a guide for promising practices in engaging LTC communities in research.[28]

Table 2 Description of Ontario Association of Residents' Council (OARC) groups involved in the project

OARC group	Participants	Meeting format and description
Resident Expert Advisors and Leaders Group	Long-term care (LTC) home residents from across Ontario who are involved as part of their Residents' Council and volunteer to provide their lived experience to OARC and OARC's partners; see: https://www.ontarc.com/who-we-are/real.html	Monthly, online. Membership of the advisory group is composed of 8–10 residents. Meetings are cochaired by LTC residents (one group member and a resident representative serving as a director on the OARC Board. Meetings are supported by OARC team members.
Education Committee	Members of the OARC Board as well as current/former LTC home residents, team members and administrators—as well as a member from a sector partner organisation (Ontario Centres for Learning, Research and Innovation in LTC.).	Quarterly, online. Committee membership of 16 people. Meetings are chaired by an OARC Board member who has extensive experience working in LTC, including in leadership positions.
Residents' Council Assistant Forum	LTC home team members (often recreation managers, recreation team members, or social workers); see: https://www.ontarc.com/residents-council-assistant-forums.html	Monthly, online. Typical attendance of approximately 10 LTC home team members and 1 OARC team member who coordinates and facilitates the group.
Resident Forums	LTC home residents living across Ontario; see: https://www.ontarc.com/resident-forums.html	Weekly, online. Typical attendance of 10–12 LTC home residents and an LTC home resident who facilitates the group.

Key concepts

In all stages of the project, our focus is on three key areas:

Population: adult LTC home residents

Other approaches, for example, exclusively engaging team members or families, are not considered in the current study.

Concept: evidence of resident engagement in LTC home organisational design and governance

Our project focuses on integrating resident values, experiences and perspectives into the design, delivery and evaluation of LTC homes. Analogous to Bombard *et al*'s review of health services,[29] we apply Carman *et al*'s model of patient engagement.[11] This framework recognises three critical aspects of engagement: (1) engagement activities range along a continuum (consultation, involvement and partnership); (2) engagement occurs at different levels (resident, home and system) and (3) multiple factors affect the willingness and ability of residents to engage. We focus on examining involvement and partnership in organisational design and governance (see table 1). Within the LTC home, such involvement may be through serving on councils and committees, participating in designing and executing quality improvement projects, assisting with team member hiring, training and development, and contributing to the design of their LTC homes' physical environment.[11] Surveys of residents conducted by LTC homes (ie, consultation) are not within the scope nor are studies of engagement in direct care (resident level) or policy-making (system level).

Context: LTC homes

LTC homes are settings that provide ongoing functional support and care for people who require assistance with daily living activities.[1] In part 1, our scoping review, we will focus on LTC homes and include other congregate living settings that are primarily for older adults (eg, assisted living or retirement homes). We draw on evidence from these other contexts to acknowledge the diverse definitions and categorisations assigned to the different types of supportive housing, and, despite the differences in the systems in which they operate (including funding and care models), the commonalities for the populations who live in them.[30–32] In parts 2 and 3, we will focus exclusively on LTC homes. Although, the findings may have implications for similar types of supportive housing.

Part 1: scoping review

The scoping review will follow the six steps by Arksey and O'Malley[33] and extended by Levac *et al*,[34] as outlined with the modifications below.

Step 1: identifying the research question

The research questions were developed and refined through deliberations with OARC:

1. How have LTC residents been engaged in the organisational design and governance of LTC homes?
2. What are the reported barriers and enablers to this engagement?
3. How have considerations of diversity (eg, related to age, gender expression and identity, culture, disability, education, ethnicity, language, religion, race, sexual orientation and socioeconomic status) been integrated into this engagement?
4. How have considerations of dementia and cognitive impairment been integrated into this engagement?
5. How has the impact of this engagement been evaluated, including with resident-centred outcomes, resident-centred experiences, resident/family/team member satisfaction or health economic outcomes?

Step 2: identifying relevant studies

Information sources

We will search electronic databases for grey and academic literature. An information specialist will create, refine and execute a search strategy (see online supplemental appendix A) in consultation with the project team. The information specialist will conduct the search in Medline followed by translation to other databases. We will search eight databases: MEDLINE, CINAHL (EBSCO), PsycINFO, Web of Science, Sociological Abstracts (ProQuest), Embase and Embase Classic (Ovid), Emcare Nursing (Ovid), AgeLine (EBSCO). These databases were chosen for their focus on biomedical science, behavioural, life and social sciences, nursing or ageing. We will include studies that engage residents in organisational design and governance (see the Key concepts section). We will not apply restrictions on language, publication location, publication date or study design. We will include reports of original data and exclude protocols, reviews, letters and editorials (unless they report small-scale studies). Articles without full-text availability will be excluded. Eligible grey literature types include conference proceedings, theses and dissertations, and association and government reports. Due to project feasibility, news articles, blogs and social media will be excluded from our grey literature search.

We will identify relevant association, government or stakeholder reports via keyword searches on websites of Canadian and American organisations that are reputable to the LTC sector (see online supplemental appendix B). When searching the organisations' websites, we will record the keywords used, the website or organisation's name, the URL and the date of the search. Allowance was made to include other relevant literature identified through stakeholder feedback or scanning through the reference list of relevant reviews and eligible grey or academic references.

Step 3: study selection

Sources retrieved through the database searches will be deduplicated in EndNote[35] and collated into Covidence for the title and abstract screening, followed by a full-text review. All reviewers will first meet to discuss their decisions on a pilot set of fifteen references to optimise congruence. Each reference will then be independently screened by two reviewers. Any discrepancies when screening the titles and abstracts will be resolved through discussion and consensus. Discrepancies during full-text screening will be resolved through discussion and consensus. We will screen the grey literature found on key organisations' websites for relevance in two stages: first, by previewing executive summaries or tables of contents, followed by a full-text review.[36]

Step 4: charting the data

Two reviewers will independently extract data for each reference using Covidence. We will collect the recommended information: author(s), year of publication, study location, a description of the study population and setting (eg, demographic characteristics of residents and characteristics of the home), aims of the study, outcome measures and relevant results.[33] The project team will design a data extraction form (see online supplemental appendix C) and then test the form on a set of ten references and modify it as needed.

Step 5: collating, summarising and reporting results

We will summarise the study characteristics in tables and analyse the qualitative data using the framework method.[37] The engagement methods will be described, including according to the residents they engage and the settings in which they take place. Relevant qualitative findings will be quoted from the reference and inductively coded to identify initial themes informed by the extended PRISM (Practical Robust Implementation and Sustainability Model)/RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) model.[38] The PRISM/RE-AIM model will guide the review of all scoping review questions except the first, which describes the engagement approach. PRISM/RE-AIM is an integrated model developed to improve the external validity of research findings[39] by considering multilevel contextual factors both external and internal, such as policies, incentives, resources, and the characteristics and beliefs of organisations and individuals. These PRISM contextual factors predict RE-AIM outcomes: reach, effectiveness, adoption, implementation and maintenance.[38] We will use the PRISM contextual factors as a framework to analyse and report our second scoping review question on barriers and enablers. Aspects of reach will guide the analysis of the third and fourth scoping review questions regarding considerations of diversity and cognitive ability. We will use all five RE-AIM dimensions to frame the analysis of the final scoping review question on evaluation (see table 3). We will report the findings in a narrative synthesis. Reporting of the scoping review procedure and findings will be guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses–Extension for Scoping Reviews.[40]

Part 2: qualitative interviews and focus groups

Engaging LTC residents in the organisational design and governance of LTC homes will introduce change for many LTC homes. Successful development, implementation and sustainability of tools/products will require a good understanding of the barriers and needs from the perspectives of LTC residents, team members and administrators.[41] We will conduct individual qualitative interviews or focus groups with LTC residents, team members (including those who provide care in and/or support to LTC homes) and administrators to assess the LTC community's capacity to implement and sustain a toolkit/resource that engages LTC residents in organisation design and governance. We will assess community capacity using PRISM as a framework to identify and

Table 3 Scoping review questions according to application of PRISM/RE-AIM

Research questions	Application of PRISM/RE-AIM
How have LTC residents been engaged in the organisational design and governance of LTC homes?	n/a
What are the reported barriers and enablers to this engagement?	PRISM contextual factors: external (eg, policies) and internal context (eg, organisational and resident characteristics).
How have considerations of diversity (eg, related to age, gender expression and identity, culture, disability, education, ethnicity, language, religion, race, sexual orientation and socioeconomic status) been integrated into this engagement?	RE-AIM: Reach.
How have considerations of dementia and cognitive impairment been integrated into this engagement?	RE-AIM: Reach.
How has the impact of this engagement been evaluated, including with resident-centred outcomes, resident-centred experiences, resident/family/team member satisfaction or health economic outcomes?	RE-AIM: Effectiveness.

LTC, long-term care; PRISM, Practical Robust Implementation and Sustainability Model; RE-AIM, Reach, Effectiveness, Adoption, Implementation, Maintenance.

describe internal and external contextual factors (see table 4).[42]

Participants will be recruited through the OARC's communication channels and other LTC networks within Ontario, Canada. We will use purposive sampling to recruit residents, team members and administrators from diverse backgrounds. Our interviews and focus groups will be led by topic guides which we will prepare based on PRISM, the findings of the scoping review and in consultation with the project team. We anticipate asking participants about knowledge, attitudes and perceived barriers and needs related to engaging LTC residents in the organisational design and governance of LTC homes (see online supplemental appendix D). We will also collect individual and home-level information from each participant, for example, demographic information, role(s) in LTC and home characteristics. All participants will be required to provide informed consent.

One or more project team member(s) will conduct the interviews and focus groups . They will be conducted

Table 4 PRISM contextual factors to be collected during the interviews and focus groups

Type of context	Factor	Examples/characteristics
External	External environment	► Municipal, provincial and national policies ► Resources ► Guidelines ► Incentives ► Social attitudes
Internal	Implementation and sustainability infrastructure	► Performance data ► Dedicated team ► Adopter training and support ► Relationship and communication with adopters ► Adaptable protocols and procedures ► Facilitation of sharing best practices ► Plan for sustainability
	Characteristics of residents	► Beliefs/belief about roles ► Perspectives/experiences ► Values ► Demographics for example, age, ethnicity, sex, gender expression ► Education/literacy ► Capacity/ability
	Characteristics of the LTC homes	► Beliefs/perspectives/values of leaders, managers etc. ► Mission and values of the organisation ► Type of organisation ► Policies and practices of the organisation

LTC, long-term care.

online (via videoconference or phone) or in-person according to the preference of the participant and logistical considerations (eg, travel distance). We will incorporate different interviewing techniques to engage with a diverse range of participants, such as incorporating accessibility aids like pocket talkers. The project will leverage OARC's experience facilitating online and in-person meetings with LTC residents (eg, see table 2).

Interviews and focus groups will be audiorecorded and transcribed. We will follow a thematic analysis process, whereby we familiarise ourselves with the data and generate codes to identify, refine and analyse themes. Data will be deductively coded using the PRISM contextual factors as a framework and then combine codes into subthemes.[43] We will use Dedoose software to analyse the anonymised transcripts. The preliminary results will be discussed with the OARC groups (see table 2) who will be involved in interpreting the findings. The final results will be presented in a narrative synthesis.

Part 3: toolkit/resource development

We will follow the codesign approach to integrate scientific evidence, expert knowledge and experience to design the toolkit(s)/resource(s) for meaningful engagement.[44 45] The project team and other stakeholders will engage in a series of workshops to codesign the toolkit/resource prototype(s); participants will include LTC residents, team members and administrators as well as other stakeholders, including OARC team members, researchers and decision-makers (see table 2). First, we will present results from parts one and two and then ask for views on critical elements for toolkit/resource design and implementation. We will use the RE-AIM framework[46] as a planning tool to establish key elements of the toolkit/resource (https://re-aim.org/applying-the-re-aim-framework/re-aim-guidance/use-when-planning-a-project/)) although critical application of the RE-AIM framework may entail focusing on a pragmatic use of key dimensions rather than all elements.[46] Second, we will obtain views on the toolkit's/resource's principles, content and format, including developing a logic model for the programme to provide a graphical representation of the theorised processes and outcomes.[47] Third, we will brainstorm resources to support and facilitate the use of the toolkit/resource. Ultimately, the outcome of the codesign process will be prototypes of evidence-informed and resident-oriented toolkit/resource that will be disseminated through academic and non-academic channels.

ETHICS AND DISSEMINATION

Research ethics board approval is being obtained for part 2 (qualitative interviews) through the University Health Network (Toronto, Canada).

The project team will disseminate the findings of the scoping review (part 1) and qualitative data collection (part 2) through publications in academic journals and presentations at conferences. Presentations will be codelivered by a researcher or an OARC team member with an LTC resident whenever possible. The focus of the presentations will be tailored to the specific audience. We will coauthor non-academic project outputs, including the final toolkit/resource) and lay summaries or infographics of other findings, with OARC team members. OARC will disseminate these non-academic project outputs using their communication channels to their network of knowledge users.

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Contributors DT, MM, GR, JL, JG and JB chose the topic and approach of the research study. JB designed the protocol and developed the scoping review questions, which were critically reviewed by MM, DT, GR, JG, BC, CM and KSM. JB and CL developed the initial search criteria. JF, JL, SH, JB and CL assisted in testing and revising the data extraction tools and inclusion and exclusion criteria. KSM and CM guided the logistics of conducting the scoping review and engagement with resident participants. DT and MM also guided resident engagement in the research method and recruitment strategies. JB and CL created the interview/focus group guide. BC, JG and GR reviewed and provided feedback for the interview/focus group guide. CL drafted all sections of the manuscript. JB provided initial revisions for the manuscripts. All authors critically reviewed, revised and edited the manuscript. All authors approved the current version of the protocol manuscript for publishing.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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